

IMMUNIZATION REGISTRY FOCUS GROUP STUDY

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American Indian, Higher Education

Tucson, Arizona

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SECTION 1: GENERAL IMMUNIZATIONS AND HEALTHCARE

I. Prevention

Diseases mentioned:

- AIDS
- Hepatitis
- Chickenpox
- Whooping cough
- Polio
- Asthma
- Measles

II. Immunizations

A. *Reasons not to get vaccinated*

- Parents forget
- May use alternative medicine[Indian doctor]
- Fear of getting the disease the vaccination is for
- The parent may abuse alcohol and neglect to have child immunized.

B. *Reasons to get vaccinated*

- Doctors tell you to
- Prevent disease
- Parental responsibility
- To keep children from getting preventable diseases

C. *Ways parents are reminded of vaccine schedule*

- Shot record booklet given at birth of baby
- Reminders from WIC
- Reminders from school

D. *Methods of easier tracking*

- Reminders sent by doctors and nurses

- Make the spacing between shots the same

I think it would be easier if they were all the same, for example, one shot is good for so many months and another shot is good for another number of months.

You have to have three hepatitis shots; then you have two—can't remember them now.

SECTION 2: IMMUNIZATION REGISTRIES

I. Initial reactions to the idea of a registry

- Respondents perceived the idea of a registry as positive. They especially liked not having to worry about lost records and the benefits of transferring records due to relocation and travel. Several expressed concerns regarding access, being put on mailing lists, and statistics used for research to categorize American Indians.

II. Content of the registries

A. Initial reactions to the type of information typically in a registry

- The reactions were generally positive and the respondents expressed little objection to the information. They generally agreed to the advantages of including the name of the manufacturer and the date. Though most of the group supported using such information one individual felt that name and birthday were not important and another felt mothers full name was not important.
- Two participants said that including information about the company that made the vaccine raised suspicion about the quality of the vaccines their child receives, i.e., are vaccines from some manufactures may be better than others.

B. Reactions to including home address and phone numbers

- The general feeling was that this information was not necessary. Some concerns were expressed that telemarketers and Internet users could gain access and use it for their own purposes.

C. Reactions to including parent or child social security number

- Respondents were generally uncomfortable with the idea of using the adult's SSN but were somewhat comfortable with using the child's. Concerns arose that with the SSN that a person's identity could be taken illegally. Several exchanged stories relating their experience with friends or family whose SSNs had been used fraudulently.

E. Reactions to including healthcare member's enrollment (WIC, Medicaid numbers, tribal enrollment numbers)

- Respondents did not see the utility of including WIC information in the registry.
- The general consensus was that for tracking purposes a new number, such as an immunization record number, should be created instead of using WIC or tribal numbers. Feelings were mixed regarding the use of tribal numbers with concerns about long numbers and the possibility of duplication of shorter tribal numbers.

III. Access

A. *Who should have access*

- Health providers
- Clinics
- Doctor and patient only
- Schools
- Grand parents
- Emergency contact person
- “Whoever you are comfortable giving it to” and the primary doctor
- When probed about whether or not day cares should have access, participants generally agreed that day cares should have access.

B. *Who should no have access*

- Insurance companies
- Politicians
- Some clinic staff
- When probed if researchers should have access, one participant said researcher should not have access. Another said providing access for research should be an option for parents.

C. *Reactions to the idea of linking registry by computer to other health information systems*

Respondents supported this idea however wanted the opportunity to give approval for what systems could be linked. There was general agreement to links if information only reflected whether or not the child’s immunizations were up to date.

IV. Consent and Inclusion

A. *Reactions to “opting out” option*

Several respondents liked this idea. A few wanted to know more about how they would receive information about opting out. They noted that some parents would forget to reply for opting out and would be entered automatically in registry. This was seen as a disadvantage to those who truly did not want their child to be in the registry. It was also seen as an advantage since more people were likely to be included in the registry with this method

B. *Reactions to consent option*

Respondents liked the idea of consent and having a choice but did note that if parents had to consent they might be forgetful which could result in less participation in the registry.

C. *Reactions to automatic option*

Respondents preferred having a choice but cited advantages for the overall health of public in case of an outbreak to have children automatically included in registry.

SECTION 3: WRAP UP AND CLOSING

I. Most important benefits of registries

- Vaccination reminders
- Children's health protected
- Easy access to information
- Reduces chance of duplicate shots

II. Greatest concerns/biggest risks

- Information being entered inaccurately
- Information could get into wrong hands

That my kid could die because they didn't put in a shot he got in the record, or that they put in the wrong shot that he didn't get. Or something like that. Some kind of mistake.

I want to know that [the nurse] signed off. I want to have that option. So we know that our signature is there and we witnessed the child getting the shot.

- When prompted about denial of health benefits and custodial issues, participants expressed little concern about these issues.

III. Influence of healthcare provider in decision to participate in a registry

General consensus that a lot of trust was placed with doctor's opinions.

IV. Suggestions/comments to people who are responsible for how system works

Information should only be given to the health provider and only with consent and only as needed in that area for outbreaks and stuff like that.

An immunization registry will benefit the people because of reminders about immunization; able to retrieve records that are lost or stolen and for information for research. My biggest concern is who can change or add information.